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ABSTRACT

A plan for a long term tracking system for handicapped children (birth to 5 years old) in Illinois is considered. The plan, based on agreements among five state agencies, could be used in a variety of ways, including for direct client care, statistical recordkeeping, and service evaluation. Advantages of an interactive system are identified, and the important elements of interagency agreements on such topics as data storage and processing are emphasized. Equipment needs and personnel requirements are considered, along with security measures to safeguard confidentiality. (CL)

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THE POTENTIAL UTILITY AND TECHNICAL FEASIBILITY
OF A COMPUTER-BASED TRACKING SYSTEM FOR BIRTH THROUGH FIVE YEAR
OLD CHILDREN WITH HANDICAPS IN ILLINOIS

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The purpose of this report is to explore the technical feasibility and potential utility of a long term tracking system for birth through five year old children with handicaps in Illinois. In so doing, the processes by which a system can be established and implemented will be discussed, along with the advantages and disadvantages of developing such a system. Since auxiliary computer technology is developing at such a rapid rate, specific recommendations for equipment would likely be outdated by the time such a plan could be initiated. Thus, computer equipment and supporting systems will not be specified. Instead, the technical capability and characteristics of this equipment will be presented, which will serve to limit choice of equipment should the program be funded for implementation. The best way to view this presentation is as a pilot framework which could be utilized as a starting point for future planning.

DEVELOPMENT OF AN INTERAGENCY PLAN

The current plan provides for an interagency agreement between five state administrative and service agencies. Interagency agreement constitutes the foundation for efficient and cost-effective services. Interagency proposals often raise the consternation of various political and agency interests. In the initial stages of implementing the interagency computer tracking system it would therefore be necessary to instill a state of cooperation and understanding. Long range planning of which this proposal is a part, is necessary so that all concerned can become involved in the development process. Each agency would need to make a commitment to and receive direct benefit from the tracking service. The system must be designed in a manner that would facilitate operating efficiency. At the same time it must not promote fear among participating agencies of loss of control. Further, a computer tracking system cannot be permitted to burden an agency or detract from service delivery; it should be facilitative. Nor should the system make any agency dependent for routine functioning. The system should be developed, monitored, and function in a way that it becomes a useful tool for each agency. It is suggested that the following Illinois agencies develop an interagency agreement for utilization of a long term computerized tracking system (alphabetically listed):

1. Department of Children and Family Services (DCFS)
2. Department of Mental Health and Developmental Disabilities (DMH&DD)
3. Division of Services for Crippled Children (DSCC)
4. Illinois Department of Public Health (IDPH)
5. Illinois State Board of Education (ISBE)

A sixth agency, the Department of Administrative Services, would appear to be the most facilitative agency which could provide the most efficient, currently in place, centralized computer site with appropriate computer equipment and support systems. Four of the above agencies currently utilize the Department of Administrative Services for portions of their information and computer-processing needs. A later portion of this report will outline reasons why the advantages of switching to a central agency would far outweigh the disadvantages.

USES OF A COMPUTER TRACKING SYSTEM

The uses of a computer tracking system are vast in scope; only the primary functions and purposes will be presented.

I) Direct Client Care

Computerized information can make readily available to the professional service provider specific client data while the client is being served. This information may be general, or may include rather complex and lengthy information regarding details of the child's problems, types of prior care, specific treatments, and the results of that care.

II) Administrative Support

Each agency must have a system to facilitate administration of services. This data base may include the quantity and types of services provided, types of equipment and materials utilized, and financial disbursements (funding and billing data).

III) Evaluation of Services

Professional, state, local, and federal agencies are currently requiring detailed evaluation of many programs. The follow-up information on clients can be provided (given proper safeguards for the individual) to organizations and/or individuals on long range outcomes after the period of care is terminated. Evaluation of the service process and quality of services will be possible both while a client is receiving services and following service as treatment outcomes. Follow-up data are necessary for an accurate, factual evaluation of the effectiveness of types of treatments and programs because the results of any program or treatment are not always fully apparent until a considerable time after treatment. The availability of a longitudinal data base makes possible the matching of service and treatment data to a variety of outcome data, thus increasing the use of the most successful intervention procedures.

IV) Statistical Record Keeping

Routine data, such as the number of children possessing each type of disability seen by each service agency, provide a valuable planning tool for schools, health planners, and administrators in obtaining future funding, modifying directions in funding and services, planning for personnel needs, and so forth. Another major function of statistical data is as a foundation for facilitating medical and social research. An agency like the Illinois State Board of Education would have consistent, up-to-date data on the number of children and kinds of disabilities that would be entering school each year.

COMPUTER SYSTEM OPTIONS

In choosing a data management system for long-term tracking, one must consider the advantages and disadvantages inherent in the various systems. For example, a system which is designed particularly for administrative purposes typically compiles and reports data long after a client interaction has occurred. A typical administrative system might involve the following steps: 1) collection and tabulation of data within one to two weeks after a client's interaction, 2) keypunching of data onto computer cards (or key to disc), 3) reading of data onto storage discs or tapes, 4) printing of data in a pre-planned format on computer paper.

There are several disadvantages to such a system. An agency that deals with large numbers of clients will have to store many reams of printed data, or transfer the information to microfiche. Access to previous client interactions becomes tedious and time-consuming. It is difficult to review the complete service system of a client, especially for ongoing service interactions. Most administratively oriented computer systems are historical in nature, with long waiting periods (perhaps six weeks) between updated reports. For agencies which require only quarterly or annual data, this system may be the most efficient and cost effective. However, these disadvantages inherent in the system's design would eventually serve to limit severely the functional abilities of a longterm tracking system for preschool handicapped children in Illinois. Therefore, this study has identified an interactive system as the preferred choice for an interagency computer system.

Administrative-Interactive Computer System. Interactive systems have the major advantage of allowing immediate access to the full data set for a specific client as, for instance, in response to a data request form from a physician currently treating a patient. The function of this immediate access would be to provide information such as the child's presenting problems over time, the specific type of care previously received, previous medications, organizations or individuals providing previous and current care, when such treatment or care was provided, its duration, and so forth.

The interactive system can be expanded or reduced in complexity by the number of data sources (agencies), and by the total number of data entries per client, depending on agency needs. For example, collection of data from a single out-patient clinic involves development of a collection instrument (form), a process for transferring and processing data, and necessary computer programs for entering, retrieving, and reporting of data. The most complete interactive system would involve a computer capable of handling interactive queries on a complete data base from various sources (agencies). That data base might consist of several common forms, or several different sets of forms which are unique to a particular data source (agency). For example, a medically oriented facility might wish to record several types of data: 1) medications a child has received; 2) whether the child is receiving physical therapy; 3) whether the child is receiving funds from a welfare source; and, 4) that the child requires an order for a specific prosthetic device. For each child or data interaction, one, a few, or only portions of the several data forms might apply.

It should be obvious by this point that what is being described here is a system which can handle relatively complete information on each child, so that the data can be collected, stored, and a good summary of information can be accessed immediately through on-line interaction. The system with the most flexibility would be designed to handle free-field type formats; that is, with optional storage space for additional data items which would allow for free text or open-ended response. A specific set of data collection forms could be designed which would reflect a rather complete reporting of a child's care. At the same time, administrative information can be collected within the same system for statistical and other informational purposes. Some agencies may only have need of statistical data, with relatively little use for free text. The design of the system could be such that confidential reports (medical, psychological, social and emotional) would be available only to a specific agency or authorized users. Herein lies the basis of a carefully designed interagency agreement which provides all access only to a common set of relevant data. A latter portion of this report will discuss security measures which can permit interagency exchange of information within current legal guidelines.

The interactive system requires magnetic disc storage to allow access of selected data on an immediate basis. For example, an agency might keep on-line client data which has been collected over the past year and/or those client's data which are considered to be "active." Other nonactive data can be stored on magnetic tape and be available within minutes of an interactive query of the data base. It is recommended that data be stored in a hierarchial or "tree" structure to allow for selection of record types and data items. Allowing free-field formats will require careful selection of a data base management system or appropriate programming language. While not necessarily more expensive than the traditional fixed-field data base packages, availability of personnel familiar with their operation and application is not as wide spread in comparison to fixed data base procedures. With the essential computer site available in Illinois (presented below), a selection of personnel and development of software (data entry programs and retrieval programs) should not be overwhelming in scope. However, pilot study and initial interagency meetings would have to occur before final selection of data format could be made. The agencies could choose not to have available relatively flexible "free text" data, and could decide that fixed base with pertinent comment data sources and unique agency data would be sufficient for their needs.

KEYS TO INTERAGENCY AGREEMENTS

A prehistory of working agreements is essential for the implementation of any new project. Four of the major agencies listed previously (DCFS, DMH&DD, IDPH and ISBE) currently utilize a central computer located in Springfield, Illinois, within the Illinois Department of Administrative Services (Offices of Management Information and Communications -- OMIC). The Division of Services for Crippled Children currently utilizes the computer located at the University of Illinois, Chicago Circle Campus. The advantage of their switching to a central computer site with on-line, immediate retrieval systems and exchange agreements with the other four major agencies should outweigh the disadvantages in the initial stages of implementation. Each agency would have to have the prior assurance, backed

by data access codes, that data unique to their system would not be accessible to another agency or exchanged without prior agreement. The software system could be designed between agencies with specific unique data exchanged only via prior agreement. Unique data (e.g., free text social and emotional reports) could have specific computer codes only available to a given agency. It becomes extremely important to understand that computer data bases are more "secure" than traditional hand-filed systems. To illustrate this point, if one were to walk into any social service agency, one would very likely see numbers of client charts stacked on desks and on the top of filing cabinets, waiting for refiling.

Common Data Base. For agencies efficiently to exchange common data, it is essential that a common client ID number system be developed. One such system might include the following (potential) common data form.

- 1) Client identification number-Social Security number, plus year of birth
- 2) Geographic code-County/Community/District-school codes
- 3) Age or date of birth (month/day/year)
- 4) Program type
- 5) Problem area/diagnosis
- 6) Specific service provided
- 7) Sex
- 8) Race
- 9) Last name/first name/middle initial

Once a client's interaction occurs within an agency and the common data has been entered into the system, immediate exchange of information can occur to the relevant agency. For example, a five year old child with mild cerebral palsy may receive a first service interaction with DMH&DD. Immediately upon entry of the common data base information (i.e., ID, etc.), the system automatically lists the child on the Illinois State Board of Education's roster as requiring special education services in the fall. In this manner, the Illinois State Board of Education could anticipate certain levels of funding needed for children with cerebral palsy in all the specific districts where these children live. Such planning is one of the primary and most basic uses of a longitudinal tracking system for preschool handicapped children. The educational and public health systems will know how many children of each specific disability requiring numerous specific services are in the total system, by location and by upcoming service system immediately upon entry.

Data Storage and Policy for Expunging Data. One of the major difficulties which would have to be addressed in the interagency agreement is the volume and the length of time in storage of data from each source. One of the agencies (DCFS) is mandated to store data by law for a period of eight years. Since the system will be designed with flexibility, and data entry will involve key to disc to tape, master files could be created on tapes of those agencies requiring longterm storage. Other agencies may wish to store data for shorter periods of time, and sub-systems could be designed to keep immediately retrievable "active data" one to two years on discs, with specific dates for expunging, updating or transfer to master storage specified.

Common Data. Agreement on a common data base and data storage system concerns represent two sensitive areas which would require a cooperative agreement among the five agencies. The common identifier information for each client should be kept as brief as possible. The concept here is to provide efficient exchange of information with a relatively simple data format that does not overburden data entry personnel at each agency's site.

Data storage concerns would likely contribute to a rather lengthy process in arriving at a firm interagency agreement. First, fear of control is common in any major cooperative agreement. Each agency would have to determine that it controls specific data entry -- the computer system does not control its operations. Second is the concern that a general degrading of services would occur when switching to new, burdening, complex reporting data forms. If the system is designed properly, each agency should be able to reduce data collection when forms overlap in data with those of other agencies. Once the common data has been entered for a client, only the client's ID number need be entered to the on-line system for immediate retrieval of the total client profile (available by agreement to the particular agency). Service personnel will not have to complete entire "inprocessing" forms upon every service interaction. Elimination of recurrent data entry would save an incalculable number of hours for many of the services currently provided in each agency. Since the "system of control" would be devised on interagency agreement, fear of control and degrading of services would occur only to the extent that the agencies permit the computer system and interagency distrust to overwhelm them. The implementation phase (presented below) and presentation of the computer system available at OMIC will provide further clarification and understanding of these issues.

CENTRAL COMPUTER SITE

Development of any new cooperative system requires trust in establishing positive work relationships. This particular project will also require technical competency in utilizing a central computer site that has sufficient computer capacity to handle the large number of client interactions which would occur. A minimum of \$500,000 in computer equipment costs could be saved by utilizing the Illinois Department of Administrative Services, Office of Management Information Complex (OMIC), located at 201 West Adams Street, Springfield, Illinois 62706. The OMIC system currently has four computer complexes:

- 1) System A--IBM 3033/MP
- 2) System B--IBM 3033/MP
- 3) System C--IBM 3031
- 4) System H-- AMDAHL 470/V8

System H actually has the capacity to handle all of the interactive computer management for the total preschool handicapped tracking system. Because the OMIC system has a demonstrated prehistory of competent management and efficient computer functioning, the initial technical requirements of a central computer site could be considered developed. As a demonstration of the technical capacity of OMIC, the following is a brief summary of the technical characteristics of the H system.

Computer Complex H System -- AMDAHL 470/V8

I. Hardware Type

- 1) CPU
 - a) AMDAHL 470/V8 (IBM Compatible)
 - b) 16 Megabytes of Storage
 - c) 16 Channel
- 2) Disc Drives
 - a) STC 8350 (IBM 3350 Equiv.)
- 3) Tape Drives
 - a) STC
- 4) IBM Mass Storage System
 - a) Comm. -- IBM 3705

II. Software

- 1) Operating System MVS REL. 3.8
- 2) RJE - JES2

III. Data Base/Data Communications

- 1) IMS/VS DB/DC REL. 1.1.5
- 2) CICS REL. 1.4
- 3) ACF/VTAM REL. 2
- 4) NCP
- 5) All Supporting Utilities
 - a) Total data management programs -- new computer programs would have to be written in the pilot phase to achieve efficient data entry, retrieval, and interagency exchange.

LOCAL AGENCY EQUIPMENT NEEDS

Each of the five state agencies would require certain local, on-site computer entry and retrieval equipment which would be linked to the OMIC system. At the very minimum this equipment would include terminals and a high speed printer.

IMPLEMENTATION OF THE LONG-TERM TRACKING SYSTEM

Personnel. Since initiation of such a project requires sensitive, understanding, and technically competent interaction between the agencies and OMIC, it is suggested that it would be wise to utilize several outside consultants in the development of the project and in monitoring the system during the first two years. Outside consultants could maintain a more unbiased yet understanding relationship with all the agencies in facilitating specific agreements and general working relationships between the various agencies and OMIC. The major consultant should have practical experience in service provision in contexts similar to the involved agencies. In addition, a detailed working knowledge of longitudinal computer systems is obviously mandatory. The major consultant would have the following primary job responsibilities:

- 1) establish liaison between key people at each agency;

- 2) determine data confidentiality protection needs;
- 3) expedite discussions regarding funding and facilitate coordination;
- 4) coordinate the investigation of specific computer options;
- 5) help establish and oversee form development and data entry committee;
- 6) be responsible for the ultimate workability of the data forms;
- 7) continue liaison efforts during the pilot and implementation phases of the project, recommending consultants to iron out details as necessary;
- 8) make recommendations for local site computer equipment for each agency;
- 9) determine package software to be utilize with the assistance of other computer technicians and early childhood specialists, as needed; and
- 10) begin the design of the system in cooperation with the OMIC systems analyst (specified below).

Systems Analyst. It would be necessary to obtain the services of a systems analyst/coordinator from the OMIC system. A one half time person for the first year of the pilot stage would be required. The major job role responsibilities for the systems analyst would include:

- 1) maintain liaison with the consultant in establishing interagency agreement for the data-entry system;
- 2) initiate and monitor the development of forms with the agency committees;
- 3) arrange for data acquisition;
- 4) supervise the training and data entry at each of the local agency sites;
- 5) supervise data entry, retrieval and storage at the OMIC system;
- 6) develop appropriate software programming for data entry and retrieval;
- 7) demonstrate the workability of data confidentiality to each agency as the system is developed with the major consultant;
- 8) work with the consultant in determining which equipment and revision of equipment capacity would be necessary, both at OMIC and each local agency site;
- 9) document the total operational system;
- 10) continue coordination and liaison with agency during the implementation and expansion phases of the project; and
- 11) establish working relationships with the systems analyst (or the equivalent) in each of the participating agencies.

It would be most important for each of these agencies to grant coordination authority for the systems analyst/data coordinator at OMIC. Since several of the larger agencies already have their own systems analyst, these personnel could work in consort with the coordinator from OMIC in developing and maintaining this system.

Interagency Governing Committee. Each of the agencies would be able to maintain control of the system through representation on the governing committee that would meet with the consultant and systems analyst during the initiation, implementation, and development phases of the project. This committee would have to arrive at interagency agreements which would initially include agreement on a common data base, data management system, confidentiality, equipment selection, and budget management. It is suggested that a rotating chairmanship of this committee be established, rather than placing sole authority in one agency. It would be important to maintain a service orientation throughout the entire development phase of the project, rather than a computer based orientation.

Initiation and maintenance of the entire project would not be without complex and difficult problems. If a five agency agreement is initiated, it is suggested that two of the agencies (for example, the Illinois State Board of Education and the Department of Mental Health and Developmental Disabilities) engage in the first pilot test of this system. All five agencies would participate in establishing an agreement with a common data base, retrieval system, equipment, and security system (discussed below). However, by limiting the actual pilot test to two agencies, the majority of the operational problems could be worked out prior to expanding to the five agency system.

SECURITY MEASURES

Confidentiality involves the regulation of data access so as to avoid any inappropriate, illegal or otherwise unauthorized use of the system. Security is most related to the question of how to disallow any access to the data by unauthorized personnel. There is an historical basis for computer systems to be disbanded under public pressure when confidentiality and individual rights have not been adequately maintained. Most of the concern has been focused on centralized computer systems, particularly those associated with large government agencies. These concerns and fears, both real and imagined, must be considered and worked on early in the planning phase of such a system. Public relations are a paramount consideration here. For example, in Oklahoma, data from a statewide and state sanctioned screening test cannot be computer scored or stored due to "irrational" fears of potential misuse of the data by a miniscule proportion of the population. State officials admit they had not anticipated nor were prepared for the negative reaction which they feel could have been avoided.

It would be necessary to maintain a reasonable "trade-off" in developing a secure computer system. At the very minimum each agency should maintain their terminal equipment in an isolated room with limited access. A log book of the arrival and departure of all personnel could be kept. The identification at a terminal could require, in addition to specific agency passwords, an individual code word unique to each operator.

This type of system should meet the major security requirements in maintaining control of each agency's data. It is difficult to imagine any monetary interest great enough for someone to risk an expensive, illicit procedure for a report of summary statistics or a list of clients though the right of privacy is at stake and must be protected at all reasonable cost.

Physical Security Measures. The area in which the computer forms, terminal, and other computer equipment is stored must be restricted to only those agency employees who need direct access because of their jobs. The computer room should be in view of other personnel on an ongoing basis. A system should be devised for reporting entry of anyone not usually in the area.

Typically, during normal working hours, the data entry personnel, programming personnel, and other computer operation personnel are in the vicinity of the computer room, and would probably be aware of unauthorized persons. The room and terminal equipment should remain locked when the computer personnel are not working.

There should be a series of access passwords relevant to each agency's set of data and specific data entry personnel. Code words should be changed on a random basis. Specific agency code words should not be available to the other agencies. The terminals should be restricted to the user mode of access so that operation is controlled by the data entry programs. An unauthorized user would have the barrier of physical access in addition to requiring knowledge of "log-on" procedures and a minimum of two passwords which are periodically changed.

More remote terminals, located at local sites would not have as large a degree of physical security. However, in each case the terminal would, and should, be installed in an area not visible to the general public. Physical access, knowledge of the passwords, as well as the unlisted dial-up phone number would still be required. It is highly unlikely that anyone would have knowledge of all three of the security items.

Security of Data Forms. Completed data forms with client information should be kept in locked facilities with restricted, limited access to only necessary personnel. As soon as the data entry has been made from the terminal, to disc, to tape, to back-up-tape, the original data entry form should be destroyed in the presence of at least two agency personnel. The consultant and systems coordinator from OMIC would be able to assist each agency and agency site in each of these physical and operational security measures.

Software Security. Software is defined as the combination of all computer programs and data that reside in the computer equipment. Computer programs are the variety of instructions that cause the computer to execute a specialized task. A large set of programs will be necessary to achieve data entry and retrieval for all client records, and there would be the expectation that these programs would grow in size as various applications from each agency were developed.

Most of the lines into the computer system are restricted to user mode, so that none can modify or delete programs from the system (as can be done in programming mode). The series of passwords limit access only to one's unique set of data, and by password to that common data exchange which has been agreed upon in the interagency agreement.

All programs and data would be stored on the computer's disc file at OMIC. It is possible, (although rare) that disc drives can malfunction, thereby expunging all or part of the disc or data bank. Other dangers include accidental loss due to an error in programming, a magnetic field placed in close proximity to the disc, fire, or other accidents. To guard against loss, a back-up disc system should be utilized. Information on the disc is copied onto a second disc which is available for use if the first is destroyed. The information lost would be only that entered since the disc was last occupied, thereby making readily retrievable the most recent data.

A routine schedule of back-up disc storage would be established on a weekly basis (initially) and perhaps once a day, depending on the volume of use. These back-up discs would be stored in a separate area from the central computer room, so that a common accident would not destroy both. Security needs of back-up discs are not so great, since information cannot be read except on another computer of the same brand and configuration, with the identical controller and disc drive, and identical programming packages. (The author of this report does not know of any one computer system which has identical configurations.) It would be important to guard against any type of vandalism, so the disc must be locked and secured in a non-public area. It is easy to see that this security system is immeasurably greater than the more typical manual handling of client records.

CONCLUSION

The potential utility of a computer based tracking system for preschool handicapped children would seem to justify its initiation. The technical capabilities remain relatively simple compared to the degree of interagency cooperation necessary. The administration of the system would require active representation by all participating agencies and an equivalence in the benefits derived proportional to each agency's investment.

While specific computer hardware and software systems have been aschewed it is emphatically stressed that such systems already exist--the specific system to be fitted to the five agencies' particular needs.

To assure the viability of such a progressive system persons outside of the agencies involved, perhaps even outside of the state, should have primary consulting roles. The enactment of such a program would keep Illinois in the forefront of special education services.

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